

**Department of Education**  
**Statement by Troy R. Justesen, Ed.D.**  
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**Office of Special Education and Rehabilitative Services**  
**on**  
**Autism Spectrum Disorders: An Update of Federal Government Initiatives and**  
**Revolutionary New Treatment of Neurodevelopmental Diseases**  
**May 6, 2004**

Mr. Chairman and Members of the Subcommittee:

Good afternoon, I am Troy Justesen, the Acting Deputy Assistant Secretary for Special Education and Rehabilitative Services at the Department of Education. Thank you for the opportunity to provide an update on the Department of Education's initiatives for children with Autism Spectrum Disorders (ASD) served under the Individuals with Disabilities Education Act (IDEA).

Over the past 28 years, the IDEA has been successful in ensuring that children with disabilities have access to a free appropriate public education. Prior to the passage of the IDEA, only one in five students had access to appropriate special education services in the public schools. More than 1 million children with disabilities were excluded from the public education system and another 3.5 million children with disabilities did not receive appropriate services. Today, more than 6.9 million children with disabilities are provided early intervention and special education services.

States reported a 1.6% annual increase from 1999-2002 in the number of children with disabilities ages 6 through 21 receiving special education and related services. The

number of children with autism, ages 6 through 21, receiving special education and related services increased at an average annual rate of 22% during the same time period. It is evident to school personnel that the number of children seeking services for autism spectrum disorders has greatly increased. Epidemiologists are investigating whether the numbers reflect more inclusive diagnostic criteria or, in fact, constitute a true increase in the incidence of autism spectrum disorders (ASD) in children.

The Office of Special Education Programs (OSEP) within the Office of Special Education and Rehabilitative Services (OSERS) administers the Individuals with Disabilities Education Act (IDEA). OSEP is committed to furthering effective evidence-based practices for children with ASD through research, model demonstration, outreach, technical assistance, and personnel training projects funded by IDEA, Part D discretionary investments. OSEP has invested \$8.6 million of discretionary funding in fiscal year 2004 for projects that addressed the needs of children and youth with autism spectrum disorders. These investments fund a total of 51 projects, 30 of which focus solely on autism spectrum disorders and 21 of which are designed to improve services and prepare personnel to meet the needs of children with ASD as part of a larger group of children with other low-incidence disabilities.

One of the most pressing challenges for school systems in educating children with autism spectrum disorders is keeping up with the increase in highly skilled personnel needed to provide appropriate services. Some of the instructional strategies that are effective for children with ASD are relatively complex and demand sufficient practice to achieve success. We have continued to focus on meeting this need since it was first

highlighted in the National Academy of Sciences Report, *Educating Children with Autism*, commissioned by OSEP in 2001.

OSEP continues to make a number of investments that are intended to prepare competent, highly trained personnel to work effectively with children with ASD in natural environments, family-focused settings, schools, and communities. For example, the Professional Development in Autism (PDA) Center is a five-year, \$5 million national research and training center that is designed to increase the capacity of local school districts, families, and communities to meet the needs of students with ASD. The PDA Center will have a national impact through a consortium of six sites across the country: The University of Washington, the University of Kansas, the University of Colorado at Denver, the University of South Florida, the Oakstone Academy in Ohio, and the Maryland Coalition for Inclusive Education. The center provides intensive, hands-on training to teams of educators. In addition to training, the PDA center will also develop and disseminate useful materials, such as instructional procedures, activity ideas, and family/child support plans for children with ASD.

OSEP is currently funding projects that specifically address the personnel-preparation needs of teachers and related service providers who will work with children with ASD and their families. These projects target various areas including early intervention, speech and language pathology, and the development of interdisciplinary personnel. OSEP also funds additional personnel-preparation projects that involve training personnel to work with children who have autism spectrum disorders among other low-incidence disabilities.

OSEP continues to assume a leadership role in identifying and disseminating effective interventions that improve outcomes for children with ASD and their families. Initiatives are under way to develop and support promising practices in identification, assessment, and interventions. For example, the average age of diagnosis for children with ASD in the United States is 3 to 4 years of age; although most families initially express concern to their pediatricians by the time their child is 18 months old.

Through OSEP-funded research projects, *Early Identification of Children with Autism Spectrum Disorders* at Vanderbilt University and *First Words* at the University of Florida, researchers have succeeded in accurately distinguishing some children with autism from children with typical development and children with other developmental delays beginning as early as 12 months of age. Early and accurate diagnosis enables very young children with autism spectrum disorders to reap the benefits of earlier intervention, using a range of behavioral and naturalistic approaches. Research indicates that intervention provided to a child before the age of three and a half has a much greater impact than that after age five. Although there have been significant advances in genetic and biomedical research on ASD, there is currently no reliable biological marker for either autism or ASD. Therefore, screening and diagnosis for ASD must be based on behavioral features.

OSEP-funded model demonstration programs have developed and implemented successful practices for working with children with ASD and their families. For example, the Seattle Public School System has adopted a program that blends several approaches to meet the needs of children, families, and school personnel, including an OSEP-funded model approach developed at the University of Washington Experimental Education

Unit. This model approach incorporates developmentally appropriate treatments, including extended instructional time, family support, transition support, and collaborative, coordinated services, within an inclusive early childhood experience to yield improved outcomes for young children with autism and their families. Other successful model demonstration projects are being replicated in multiple states. For example, the *LEAP Learning Experiences* outreach project at the University of Colorado at Denver is being replicated in three states. This program provides training to early intervention staff working with children with ASD. *Project DATA*, developed at the University of Washington, has expanded to an outreach training project designed to help district personnel implement and evaluate school-based programs for young children with autism.

Addressing the often-complex needs of children with ASD is a salient research and practice issue. Autism Spectrum Disorders are characterized as a triad of disabilities that include communication, social interaction, and restrictive or repetitive behaviors. In order to address the need for research on communication skills for children with autism, Northeastern University is examining whether speech output from synthetic or digitized speech-generating devices will result in more efficient requesting and vocalizations among students with autism.

Current intervention and practice projects related to ASD include the *Early Social Interaction Project* at Florida State University, which is designed to teach very young children with ASD in natural environments, and a project at the University of Florida through which an evidence based curriculum is being developed to facilitate social success of young children with autism in natural settings.

Autism spectrum disorders pose unique and difficult challenges for families. The Department is committed to addressing these challenges and supporting families through a variety of projects. For example, a project through the University of Massachusetts at Boston addresses parent involvement in public school programs, while *FAMILY LINKS* at Case Western Reserve University uses a developmental, relationship-focused intervention for children with autism. *Project TASK* in Ohio addresses the needs of children with autism as they move to school from kindergarten.

To maximize the impact of the Department's initiatives on behalf of children with autism spectrum disorders, OSEP maintains ongoing partnerships with the medical research and practice communities and with other Federal agencies. The Interagency Autism Coordinating Committee (IACC), chaired by the National Institute of Mental Health, is one example of a formal Federal agency partnership.

The Department has participated actively as a member of the IACC since its first meeting in 2001. Through the work of this Committee, the Department is able to exchange information on autism initiatives among government agencies and with advocacy and other groups focused on autism, and improve the coordination of autism-related activities.

In a joint effort, the IACC, with the Department of Health and Human Services and the Department of Education, hosted the Autism Summit Conference in November 2003. This conference complemented the activities of the several government organizations that have been members of the IACC since its inception. At the conference, IACC members discussed a ten-year plan for implementation by Federal

agencies to address research goals and activities focused on enhancing understanding of the causes and best treatment options for autism.

OSEP funds technical assistance centers and projects to assist states in implementing effective evidence-based practices to support children served under the IDEA. Centers, such as the National Early Childhood Technical Assistance Center in North Carolina and the National Center on Dispute Resolution in Oregon, continue to focus resources on ensuring that information on effective practices in ASD and other disabilities are made available to State Educational Agencies.

OSEP-funded Parent Training and Information Projects and Community Parent Resource Centers in 50 states and in many communities provide information and advocacy for families of children with disabilities, including autism, as they address their child's complex developmental and educational needs. Access for all families of children with autism spectrum disorders, regardless of family resources, to programs based on effective, evidence-based, well-implemented, models remains the highest priority.

In closing, students with autism spectrum disorders present unique challenges to families and schools. The IDEA Part D programs play a critical role in supporting states and local districts in providing evidence-based practices for children with disabilities and their families, including those with autism spectrum disorders, to help ensure that no child is left behind.

That concludes my prepared remarks. I will be happy to answer any questions.